

# Undercounts and Overstatements: Will the IOM Report on Lesbian Health Improve Research?

## ABSTRACT

In January 1999, the Institute of Medicine (IOM) released a report on lesbian health research that fulfills 3 goals: it provides an extensive review of much of the research that has been done on the health of women who have sex with other women, it addresses the methodological and ethical issues inherent in conducting research on this population, and it suggests avenues for further research. This report will likely help lesbian health researchers gain funding, publish further research in medical journals, and receive support and validation from medical and research institutions. To ensure that such research is useful, benefits the lesbian community, and expands the understanding of lesbian health conditions, particular attention needs to be paid to the methods and definitions used and to the involvement of the lesbian community in designing, implementing, and analyzing the research itself. (*Am J Public Health*. 2001;91:873–875)

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For decades, health providers, researchers, and lesbian health activists concerned about the medical establishment's lack of attention to lesbian health issues heard a constant refrain from research funders, medical journal editors, and public health authorities: "Give us published research on these issues and we will listen to you." The classic catch-22 of this response has frustrated the lesbian health community: Without funding we cannot do quality research, without quality research we cannot get published in medical journals, without being published in medical journals we cannot convince health experts that a health need exists, without proving to health experts that a health need exists we cannot get funding for research, prevention, or programs.

Then, Dr Vivian Pinn was appointed director of the Office of Research on Women's Health at the National Institutes of Health (NIH). As a heterosexual woman, she was an unlikely leader in the lesbian health movement, but she has had a significant impact. Encouraged by the advocacy of lesbian, bisexual, and transgender health activists across the country, Dr Pinn found a way to address the need for research on lesbian health.

Through Dr Pinn's efforts, the NIH and the Centers for Disease Control and Prevention (CDC) funded the Institute of Medicine (IOM) to produce a report on lesbian health research priorities. As a significant institute within the National Academy of Sciences, the IOM is perhaps the most highly regarded voice in medicine. Dr Pinn's insight into the health establishment, and her understanding that nothing short of an IOM report would get the attention of medical providers and researchers, bring us to this historic moment.

The IOM report,<sup>1</sup> released in January 1999, fulfills 3 goals: it provides an extensive review of much of the research that has been done on the health of women who have sex with other women, it addresses the methodological and ethical issues inherent in conducting research on this population, and it suggests avenues for further research. This report will likely help lesbian health researchers gain funding, publish further research in medical journals, and receive support and validation from medical and research institutions.

## Research Not Always Benign

Research is an important tool for obtaining invaluable information about the health risks, needs, and behaviors of the individuals being studied. It is also a double-edged scalpel, as capable of exploiting minority communities as it is of advancing their healing. From the Tuskegee syphilis experiments on 412 African American males—which lasted from 1932 to 1972—to the unethical double-blind HIV/placebo drug trials of African women in the late 1990s,<sup>2</sup> medical research has shown again and again that it is not always benign.

Research on gay communities has often failed to describe how truly diverse we are, yet this limited research has then been used to further stigmatize us. For example, market research reporting high disposable income among gays, biased because its information came mainly from gay readerships of glossy publications, has been used within the court system to challenge gay civil rights laws by depicting gays as White and affluent (and thus hardly in need of a minority's civil rights protections).<sup>3</sup> Similarly, low response rates to the question of who identifies as gay or lesbian have been used to hurt the lesbian and gay community politically. In 1994, for example, prior to the third Gay and Lesbian March on Washington, the National Opinion Research Center study reported that 0.9% of 1749 randomly selected women self-identified as lesbian and 2.0% of 1410 randomly selected men self-identified as gay.<sup>4</sup> The Far Right then touted this undercount in the media to bolster their dismissal of the gay community as a very small minority and thwart the political platform of the gay civil rights movement that spawned the march.

The IOM report may improve opportunities for research on the lesbian community, but will it improve the quality of the methods or the completeness of the analysis? To ensure that such research is useful, that it benefits the lesbian community and expands the understanding of lesbian health conditions, particular at-

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This commentary was accepted February 6, 2001.

tention needs to be paid to the methods and definitions used and to the involvement of the lesbian community in designing, implementing, and analyzing the research itself.

## *The Hierarchy of Methodology*

The role of the scientific method and epidemiology in public health has been debated in recent issues of the Journal. What is knowable about a population and its health conditions cannot be found solely through quantitative science. Community knowledge, particularly in the case of populations that are difficult to find or to categorize, plays an increasingly important role in attempts to study these populations. The nature of traditional science, with its levels of certainty rather than absolute certainty, makes the very knowledge it purports to represent tentative at best.<sup>5</sup> And while scientists often consider community knowledge as unreliable, biased, and politically motivated, the practice of science itself reflects values and assumptions in its choice of research topics, methods, and analysis.<sup>6</sup> An example of how institutional science works against community knowledge is the hierarchy of research design.

According to this hierarchy, one of the most reliable research designs is the random sample (a method that allows studying a small group that, because of the way it is chosen, represents a much larger population). The random sample is the standard against which all other research methods are judged. Established when research was being conducted primarily by and on White, heterosexual men, this design raises significant concerns for lesbian health research today. Random sampling requires that each individual in the community has an equal possibility of being chosen for the study. A community that includes individuals who are not sure of their sexuality or are fearful to acknowledge it, however, requires research methods that are more complicated and therefore more costly than random sampling.<sup>7</sup>

Perhaps one of the most significant effects the IOM report will have on the research community is to encourage a paradigm shift in the current hierarchy of methodology. One of the conclusions the IOM committee draws is that “[r]esearch on lesbian health, especially the development of more sophisticated methodologies to conduct such research, will help advance scientific knowledge that is also of benefit to other population groups, including rare or hard-to-find population subgroups and women in general.”<sup>1(p9)</sup>

If lesbian health research adds to the field of research on stigmatized, hard-to-reach populations, for example, by expanding innovative designs like network sampling and by im-

proving on other qualitative methods, we will have added greatly to our society in general and, we hope, avoided some of the pitfalls of past quantitative lesbian health research, which has largely undercounted us.

## *What Is a Lesbian?*

One of the difficulties of designing research on lesbians is knowing exactly who composes the population. It was a lesbian at the CDC who coined the now infamous “definition of a lesbian” that has outraged lesbians working to reduce the incidence of HIV among other lesbians for more than a decade. In the late 1980s, this researcher published a report that defined the term “lesbian” to fit her own research criteria: women who had had sex only with other women since 1978.<sup>8</sup> Assigning identity to behavior in this way was then repeated by subsequent researchers who referred to women who had sex with both women and men as “bisexual” and then concluded that bisexual women were at greater risk of HIV infection.<sup>9</sup> Not only is this definition of “bisexual” inaccurate, it is potentially dangerous, because women who identify as lesbian but have sex with men may not understand risks associated with their actual sexual behaviors.<sup>10</sup> Behavior puts individuals at risk; identities do not protect us.

It should be understood that reporting sexual behavior alone would also be limiting. There are differences between a woman who has had sex with both men and women her entire life, a woman who was sexual with men for most of her life and then started being sexual with women, and a woman who only had sex with other women for most of her adult life and is now sexual with a man. All 3 of those women might answer a question about their sexual behavior by saying they have been sexual with both men and women throughout their lifetime, but their experiences are not comparable. Whether a woman has had sex with both men and women, and what proportion (and portion) of her life she has been sexual with either, will have a bearing on her current health risks.

Does the term “lesbian,” then, have any utility in health research? Some have defined the term as a sociopolitical one that encompasses a variety of behaviors, desires, and affections for different sexes under varying circumstances. Others believe that it inherently suggests a primary, if not sole, affectional sexual relationship between women (and some believe that the definition should include only women born female). Whether one identifies as lesbian is further affected by social attitudes, particularly homophobia. Furthermore, some believe that identities should never be assigned

or ascribed, but only self-reported, with meanings determined by the person assuming the identity.

For these reasons, it is difficult to base scientific study on what a person considers her sexual or social “identity.” Yet the term “lesbian” may have significant meaning to some individuals, and the difference between which women use the term when referring to themselves and which women do not might be important to understand.

In reanalyzing the results of the National Opinion Research Center survey, the IOM committee found that, in fact, 8.6% of the women surveyed reported some adult same-sex sexual desire, behavior, or identity.<sup>1</sup> The reanalysis clearly shows that sexual orientation is complicated by various combinations of desire, behavior, and identity. And while the reanalysis is helpful, it still does not take into account that some women might have declined to participate in the study or provided inaccurate information because of their discomfort or fear. In one ethnography, twice as much same-sex sexual behavior was reported in a women’s prison as was found in the same prison in a structured research interview.<sup>11</sup>

The changes in our sexuality over a lifetime, the waning and waxing of our desires, behaviors, and identities, are arguably difficult for quantitative scientists to take into account in their research. To be most accurate, researchers should take great pains to describe behavior, desire, and identity data as they are reported by the subjects in their studies and not to extrapolate from these reports (whether by misbelief or expediency) any meaning that is not explicit. It is critically important that researchers heed this warning. Flaws in the original design or analysis of a study become harder and harder to recognize as others simply cite the study’s conclusions. Until we know who “we” are, it is going to be difficult, and rife with inaccuracy, to count us. Studies that focus on gathering qualitative data will be more successful in beginning to draw an accurate picture of who lesbians are.

## *Researcher–Community Teams*

The IOM committee repeatedly heard one major theme from members of the lesbian and bisexual women’s community seeking to protect the community against well-meaning but ill-informed researchers: the community must be involved in the development, implementation, and analysis of research conducted on us. Luckily, there is ample history from decades of community-based and participatory research on how to build true researcher–community teams. This is important even when the researcher is a lesbian herself.

The identity termed “lesbian” is so complicated that an individual lesbian researcher could not be assured of understanding what that identity means to the different women who might claim it. The added diversity of sizes, colors, classes, and ethnicities (and, some would argue, genders), the individual ways and means of coming to terms with our sexuality and identity, and the meanings we ascribe to those factors are as varied as flakes of snow. To ensure that our research has a chance of discovering the diversity of our community, we must have in place at the outset research committees that represent that diversity.

In the participatory research model (also called participatory action research), community members are considered equal partners with the traditional researcher in the research project. The partners work together to identify the research question, develop the research plan, carry out the research activities, interpret the results, and disseminate information to the community.<sup>12</sup> Participatory research is unlike any other research in that its purpose is not simply to answer questions but also to give communities tools they need to create social or political change, or both. Those tools can include the results of the research, which can be used to affect policy, or the development of research skills within a community that can then produce more researchers. Conducting research should therefore provide opportunity

for education and empowerment of individuals and communities, and the results should be useful for improving the lives and conditions of the community being researched.<sup>13</sup>

## Conclusions

The IOM report on lesbian health research might very well encourage more research on lesbian health. To ensure that research is accurate and not used to further stigmatize us, researchers and community members must form teams to develop, implement, and analyze studies. They must pay particular attention to the fact that sexual desire, behavior, and identity are complicated and still relatively unknown variables, and take care neither to undercount us nor to overstate the results by drawing conclusions for the supposed whole based on inadequate sampling. □

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